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# **Tales of the unexpected**

## **Involving older carers as co-researchers<sup>1</sup>**

### **Introduction**

Researchers embark upon their research ventures for a number of reasons, for instance, to generate or test theory thereby adding to the existing body of knowledge, or to examine a particular area of interest for deeply held personal reasons. There are a number of reasons why I wanted to undertake this particular piece of research. I wanted, for example, to create a naturalistic case study capable of generating new insights into the lived experience of older carers.

Specifically, I wanted to understand better the following propositions:

1. Older carers have the knowledge, skills, ability and motivation to act as co-researchers and they want to be involved in research that makes a difference.
2. Supporting older carers to assume the dual role of study participant and co-researcher leads to a better understanding of the complex relationship between the heroic and the mundane, the ordinary and the extraordinary. In other words, the everyday business of being an older carer in a world in which they are 'inappropriately invisible' (Royal College of Nursing (RCN), 2004, p.7).

### **Research aim/question**

A comprehensive literature search found a number of studies and papers outlining the difficulties faced by older carers of people with dementia

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<sup>1</sup> This research study was undertaken in part fulfilment of an MSc in Nursing with the Royal College of Nursing and Manchester University. The dissertation supervisor was Conal Hamill.

(Lewis, 1998) mental illness (Murry and Livingstone, 1998) and learning disabilities (Maggs and Laugharne, 1996). However, no studies could be found focussing on the needs of older carers *par se* (also noted by McGarry and Arthur, 2001) or studies in which older carers had an active role throughout the research process. Despite a number of government initiatives designed to end discrimination against older people (Department of Health (DH), 2001; Phillipson and Scharf, 2004; Scharf, *et al.* 2005; DH, 2006) it appeared to me that the invisibility (and therefore vulnerability) of older carers remained problematic. This led to the development of the following research question:

‘What does it mean to be an older carer?’

### **Definition of key terms**

To ensure that the phenomenon under scrutiny is investigated as “... it truly appears or is experienced...” Omery (1983, p.176) proposed the phenomenological researcher approach the subject with “...no preconceived operational definitions”. Benner, a fellow phenomenologist also downplayed the importance of operational definitions in interpretative research believing instead that the use of exemplars “...allow the researcher to demonstrate intents and concerns within contexts and situations...” (1994, p.117). Stake (2006), a qualitative caseworker, captured the subtle nuances and situational complexities of qualitative case study research through the use of vignettes embedded within the narrative.

While I did not work towards operational definitions in the study, I have used a number of terms, which for the sake of clarity, I have outlined below:

- The case: The ‘case’ in case study research has been defined by Sandelowski (1996, p.526) as “...always orientated toward understanding for some purpose a One, whether that one is a singular entity, such as a person, or an aggregate or spatio-

temporally defined entity, such as a family, organisation, cultural group, or event”.

- Case workers - the term applied to case study researchers
- Actors - people who are actively involved in the case
- Readers - the potential audience of the finished report.

### **The ‘case’ in this case study**

In this study the case was defined as older adults over the age of 55 who were actively engaged in providing informal (unpaid) caring activities for an adult dependent, i.e. spouse, adult child, parent or other family member.

### **Why qualitative case study?**

Robson (1993, cited in Vallis and Tierney, 1999/2000, p.21.) described case study research as an “...empirical investigation of a particular, contemporary phenomenon within its real life context using multiple sources of evidence” (a position also supported by Stake, 1995; Yin, 2003) making it, I believe, an ideal tool to describe the lived experience of older carers. Characteristic of case study research is its ability to ‘make real’ subjective experience - in this case the issues and concerns of older carers. Moreover, the person-centeredness of case study research means it is ideal for answering, ‘What are the issues here?’ questions, as reality is described and shared meanings are constructed *together* ensuring a truthful description of the phenomenon under investigation.

### **Why older carers?**

Campaigning organisations such as Carers UK, Help the Aged and Age Concern have worked tirelessly to ensure that the needs of carers are central to the Government’s emerging political agenda, culminating in the recently published New Deal for Carers strategy (DH, 2007). While older carers - along with younger carers - will benefit from changes to existing funding streams and the creation of new ones, the needs of older carers are particularly challenging and to date they remain relatively under reported in research. Few older carers are involved in research as active

partners which means that most of the information available - while essential in its own right – does not provide a personal account of the hidden work and world of older carers. One of the key aims of this study therefore was to develop a participatory methodology capable of involving older carers as co-researchers, in a study that sought to make visible their hidden work and world.

Advances in the field of health and social care have resulted in an increasing number of people living longer and healthier lives. While vulnerable people generally are undoubtedly enjoying increased longevity – it must be noted that their carers are growing older too. When this information is linked to the health risks associated with growing older, i.e. stroke, heart disease, diabetes, dementia, cancer, mental illness (for example depression) and a range of musculoskeletal disorders, it becomes startlingly clear that older carers (and their adult dependents) face a range of challenges that younger carers do not. Add to this the reality that older carers are under represented in almost every field of research (Gurwitz, *et al.* 1992; Larson, 1994; Steele, 2004), and what we could end up with is the effective silencing of some of the most vulnerable people in society.

### **Why now?**

Despite the fact that “Public involvement in research has now become a central plank of NHS Research and Development policy...” (Thompson *et al.* 2005) health and social care professionals have been slow to take up the gauntlet, which has resulted in older people in general - and older carers in particular - being excluded from research, either as participants or co-researchers. In fact, research by the Social Care Institute for Excellence found that older people are excluded from research simply because they are old (Carr, 2004). I believe the question therefore is not so much ‘why now?’ but ‘why not?’

## **Methodology**

The world of older carers is so under-represented in research that exploring any aspect of their lives would doubtless reveal a valuable seam of rich, deep and original insights. I was very aware however, of the necessity to focus on just one aspect of their lives. So, for the purposes of this study, I focused on how each older carer perceived and interpreted their unique experience in a range of situations, which I hoped would present the reader with multiple views or interpretations of the described experience. A naturalistic, interpretivist approach to data collection and analysis was adopted. This encouraged data triangulation through the use of multiple methods of data collation.

## **Site selection**

In naturalistic research, the selection of the research setting is of particular significance. Morse and Field (1996) for example, pointed out the importance of visiting the research setting before the development of the proposal to gain the permission and cooperation of staff. With this in mind, I visited several settings before making my final choice. Older carers could not be involved in making this decision, as this had to be decided before I submitted the research proposal to research ethics and research governance committees. After much deliberation, I decided to hold the focus group meetings in a local Church community hall. I did this for a number of reasons:

1. The Church was near to the town centre and conveniently situated on the main bus route;
2. All of the facilities were on the ground floor with good access for disabled people;
3. A lunch club was held every Thursday, providing a tasty lunch at a very reasonable cost;
4. There was a separate meeting room where older carers could meet in private after lunch;
5. The meeting room was available at no additional cost;

6. Staff at the Church were extremely friendly and sympathetic to the aims of the study.

Of particular significance to me was the provision of a hot midday meal in a relaxed setting. I believed that creating space for older carers to get to know each other socially would be pivotal to the success of the study. It is always a good idea to start small group meetings with a couple of icebreakers to put people at ease. However, I wanted to do more than just put people at ease. I wanted to demonstrate my appreciation of the commitment older carers had made to the study (by providing a tasty lunch and an opportunity for some social chit-chat), and I wanted to get them in the mood for story telling (Jackson and Esse, 2006).

### **Ordinary spaces as research settings**

Miles and Huberman (1994) attached so much importance to the management of the research setting they suggested including a room-plan in the appendices of the research report. Richards (2005, p.24) on the other hand talked about the setting in terms of "...entering the field" and the requirement upon the researcher to map the physical, social and cultural terrain. I spent a lot of time thinking about these issues, as I was very aware of the necessity to provide a safe space for older carers to share their stories and for me to conduct my first 'real' research study. I thought my efforts to map out the physical, social and cultural terrain had gone mostly unnoticed by the older carers. As the next vignette illustrates however, they understood my game plan, perfectly.

*The issue of keeping everyone 'on task' is a prickly one. For instance, reading the diary entries aloud prompted the reader to set the entry in its wider context – so that it made more sense to the listeners. Often these diary entries prompted other carers to retell other closely related stories, adding depth and richness to the original story. However, stopping these digresses when they become more than once removed from the original, proved tricky. This was noted by the carers themselves who assumed a self-*

*moderating role by saying “We can only talk about things like that when we are over there (pointing to the previously laden table), once we come over here (indicating the circle of chairs) we have to concentrate on what’s important to the research”.*

## **Sampling issues**

Morse and Field (1996, p.65) postulate that ‘appropriateness and adequacy’ are the guiding principals of qualitative research.

**Appropriateness** – “...is derived from the identification and utilisation of the participants who can best inform the research according to the theoretical requirements of the study”.

**Adequacy** – “this means that there is enough data to develop a full and rich description of the phenomenon – preferably that the stage of saturation has been reached – that is, that no new data will emerge by conducting further interviews, and that all negative cases have been investigated”.

In intrinsic case study, the sampling strategy is particularly important. This is because, caseworkers are interested in the everydayness of ordinary life, of discovering how people, “... function in their ordinary pursuits and milieus ...” (Stake, 1995, p.1). Although readers may identify with some of the experiences described by the actors in the case, intrinsic case study is not about generalisation, i.e. does this affect other people? It is more about illumination and rich description, and the generation of ideas and questions, e.g. how does this challenge my assumptions? Although it does not set out deliberately to build theory, intrinsic case study does contain the building blocks of theory. Phenomenologists sometimes veer away from talk of theory building in qualitative research. Richards (2005, p.129) however pointed out that although some outcomes are best described as explanations or understandings, there is no need to ‘duck for cover’ when the issue of theory is raised.



In naturalistic studies, purposive sampling is often used to identify the people best placed to describe the phenomenon under investigation. Since so little was known about the work and world of hidden carers, and my goal was to enable older carers to reveal their hidden world, revelatory case sampling appeared to be the sampling strategy of choice. As the phenomenon under investigation was older carers and their perceptions on caring, I believed the best way to gain an in-depth understanding was to engage with the carers directly. In the first instance, I believed this could be achieved by writing an introductory letter to all GP registered older carers over the age of seventy-five. However, due to a lack of response from GP practices, it was necessary to lower the age range to include older carers aged fifty-five and older and to hold an introductory meeting at the one GP practice that responded. This meeting, together with the introductory letter and participant information sheet was successful in recruiting enough older carers to take part in the study and in turn generated enough raw data to satisfy Morse and Field's (1996) requirements for adequacy.

### **Data collection**

Data produced by naturalistic case studies are not predictive. Rather, it is the intrinsic value of the case itself, its uniqueness – or sometimes its ordinariness and its ability to describe, explore or explain aspects of the phenomenon under investigation that is of importance (Stake, 1995; Yin, 2003). Data produced by naturalistic case studies can be derived from a number of sources, i.e. documentation, archival records, interviews, direct observations and participation observation. However, Yin (2003) suggested that the usefulness of data from these sources of evidence could be maximised if utilised in conjunction with the following three principles of data collection:

1. Use multiple sources of evidence
2. The creation of a case study database
3. The maintenance of a chain of evidence

Triangulation of the data in this way produces reliability and the development of 'converging lines of inquiry' (Yin, 2003, p.98). In this study, I attempted to integrate these data collection principles into the study by:

1. Gathering data from a range of sources, i.e. research diaries, focus group meetings, current and archival records, etc.
2. Completing numerous memos and field notes, and
3. Generating a large number of audit trails.

The need for me to generalise from this case to other cases was of secondary importance. Although, I was interested in what Stake (1995) described as "Teasing out complex relationships, probing issues and aggregating categorical data" (p.77), as this was intrinsic case study and my primary task was to understand the case itself, I utilised in the main, direct interpretation.

### **Data analysis**

According to Miles and Huberman (1994), qualitative data analysis has been shrouded in mystery and uncertainty for too long. Even the language of qualitative data analysis can sometimes have more in common with the ephemeral or mystical, with meanings *arising out of the data*, rather than being diligently *uncovered* by the researcher (Richards, 2005).

I believe the purpose of collecting and analysing qualitative data is to take fellow researchers, and other readers of the report, to a place they may not have been to before. The job of the researcher however, is not to map out the whole terrain, but to provide an easily understandable guide, so that others can take the same journey and expect to get a similar view of the landscape - albeit from a different hillside. Stake (1995) put it this way, "The function of research is not necessarily to map and conquer the world but to sophisticate the beholding of it" (p.43). In their attempt to "... sophisticate the beholding of it" caseworkers must remain vigilant in their

endeavours to maintain their interpretative role throughout the research study and nowhere is this interpretative role more in evidence than during the process of data analysis.

### **Interpreting the data**

Like qualitative data collection, qualitative data analysis typically follows a non-linear, iterative route, requiring the researcher to continuously cycle back and forth through the data amassed by meetings, interviews, memos and reflective notes (Miles and Huberman, 1994). During this study it was at times difficult to clearly differentiate between the processes of data collection and data analysis as the two processes so often occurred in concert, as illustrated in the vignette below:

*During that first introductory meeting with the older carers at the GP Practice, it soon became clear that two of the older carers did not want to take part in the study and had only attended the meeting out of curiosity. At the beginning of my 'talk' I had pointed out that in order for the study to go ahead, I would need at least five or six people to take part. Glancing around the room, the older carers who wanted to take part were quick to note that I needed more recruits to make the study viable. They then began to persuade those older carers (who were unsure) of the merits of the study and what, as older carers, they would gain by taking part.*

*I experienced a slightly uncomfortable feeling of being 'sidelined' and began to ask myself a number of questions, i.e. did the older carers think I hadn't presented a strong enough case, were they using their leverage as fellow carers to persuade others to join, should I 'allow' the older carers to continue trying to persuade the hesitant. All these thoughts were occurring as I attended to the practical activities of writing up the notes and ensuring everyone had enough refreshments. In fact, if I am honest, I used the excuse of carrying out these activities to watch how everyone reacted to the positive arguments being put forward by the small group of older*

*carers who wanted the study to go ahead. I was both pleased that the older carers wanted to support the study and a bit uncomfortable with the notion that I hadn't done a good enough job of 'persuading' them myself.*

Field notes like this capture the fact that caseworkers begin pursuing their lines of inquiry long before they put pen to paper. Snatched conversations, personal experience, news items, images and thoughts all play a part in shaping the outcome of the final study (Stake, 1995). This problem - of boundaries in case studies - has been noted by Hitchcock and Hughes (1995, chapter in: Cohen *et al.*, 2000, p.182), who make a number of useful suggestions designed to overcome some of the difficulties associated with the collation and analysis of case study data. With their suggestions in mind, data was collected and analysed within the following boundaries:

- Geographical – I identified a town in northern England
- Organisational setting – I invited GP surgeries within the town to take part in the study
- Group characteristics – the sample consisted of older carers over the age of 55
- Role/function – older adults aged 55 and over engaged in providing informal care-giving activities in the family home
- Temporal – the study was completed within eighteen months.

The whole point of case studies, particularly intrinsic studies, is that they have the ability to transport the reader into a different world, if you like - into a parallel universe, which at first glance presents a landscape not dissimilar to our own, but which, upon closer inspection reveals a world teeming with unfamiliar nuances. This is not unknown territory – for indeed it is extremely well trodden by the actors that make up the case, it is just not known to the reader. To become acquainted with the complexities of the case to this degree requires constant exposure to, and

interpretation of, the data as they are uncovered by the researcher. The adoption of an interpretative stance from beginning to end of the study was therefore vital for me in following the many nuanced conversations that became an integral part of the focus group meetings.

Silverman (2005) noted the non-linear progression of naturalistic research and wrote with enthusiasm about the potential for discovering new insights and new lines of enquiry while 'zigzagging' through the research process (p.4). Without doubt, zigzagging between data collection and data analysis activities created a number of serendipitous moments (particularly during the focus group meetings); when I would suddenly have an 'Aha' moment of total clarity – usually right before everything became cloudy again.

### **The unit of analysis**

In this study, the unit of analysis was the stories older carers shared, the interaction between older carers and the interaction between myself and the older carers.

### **The level of analysis**

Analysis (or data reduction) took place on seven levels:

1. Research diaries were completed at home and then read through at a focus group meeting. Anecdotal reflections that added context and significance to diary entries were added as the diaries were read aloud by older carers.
2. Prominent themes from the research diaries were identified and used as a focus for questions at the next focus group meeting.
3. At the next focus group meeting the previously identified themes were expounded upon in greater detail with many examples being offered by older carers. This meeting was audio-recorded.
4. At the third focus group meeting, older carers went through the typed up manuscript of the previous meeting sentence by sentence, marking with a highlighter pen anything they found to be significant. This meeting was also audio-recorded.

5. As we worked through the manuscript, older carers expanded upon why something was being highlighted and in this way, further revelatory insights were added to the manuscript.
6. I then went through the field notes, memos and typed up manuscripts and identified where the study's propositions and sub-themes were most strongly illustrated or confounded.
7. Literature (grey and mainstream) from the fields of health, social care, education, psychology and business was searched and used to provide context for the study's propositions.

### **Data reduction**

Just as the interpretative role of the researcher is in evidence before a study even begins, so data reduction activities begin even before the study has been formally written up (Miles and Huberman 1994). Experienced and inexperienced researchers alike play around with different ideas on how to collect, analyse and report the data. Ideas come and go until finally the most salient ones are taken forward and formalised in the research protocol. Charting the decisions made even at this early stage of the research process is crucial if novice researchers are to understand how to filter out unnecessary noise in order to fine-tune their own unique instrument.

### **Ethical issues**

During the data collection and data analysis phase of the study, ethical issues were never far from my mind. For example, the selection of tools to collect and analyse the data was made only after an exhaustive review of the literature on participatory approaches. Research diaries and focus group meetings were chosen as the two main approaches to collect primary data as I anticipated their 'everydayness' would ease the fears of my novice researchers, releasing them to share their stories. Research diaries in particular were selected because of their ability to promote inclusion (Lewis and Massey, 2004). But, to ensure all potential participants would be able to complete a diary on a regular basis, I first had to think about and plan for the following:

- For participants who may be visually impaired, the option to record their diary using a Dictaphone was made available.
- I had to be prepared to have all the research diaries, minutes from focus group meetings, field notes and memos, etc., available as audio recordings.
- I had to be prepared to either read through all associated documentation myself, or employ a reader; to ensure those with a visual impairment were not disadvantaged.
- I needed to think about the use of translation services for people whose first language was not English and for users of British Sign Language (BSL).

The sociable and relaxed nature of focus group meetings meant that they were ideal for generating a creative atmosphere. However, to enable older carers to attend the focus group meetings, I first had to put in place:

- A contract with a domiciliary care service approved by the local council to work on an hourly basis, to enable older carers to leave their dependent adult at home and attend the meetings.
- A meeting hall had to be located that offered good and easily accessible facilities.
- A contract with Church staff re payment for the lunches and refreshments.
- A contract with the local WRVS to transport older carers safely to and from the focus group meetings.

These were, of course, just some of the necessary *practical* actions I needed to undertake, if I wanted to carry out ethically responsible research. The importance of tackling these issues was obvious, even to me - a beginner researcher. However, the more subtle issue of the power of the researcher over the researched was not so obvious, nor easy to navigate. Price (2002) concerned about the issue of researcher power, pointed out 'Appropriately briefed respondents have power over the level

of responses they decide to offer' (p.273). In an attempt to appropriately brief the older carers, I included them in as many elements of the study as possible, but the fact remained that it was I who set the research agenda, not the older carers. It is for this very reason that from the very moment the researcher identifies an area worthy of investigation, he/she needs to think about the most appropriate methodology, how data will be collated and analysed and the most appropriate arena in which to publish the results (Morse and Field, 1996). When vulnerable people - such as older carers - are involved in research the 'fit' between the underlying philosophy, the methodology and the research approach assumes an even greater importance.

Older people have been identified as one of a number of vulnerable groups who are at risk of exploitation in unethical research studies (RCN, 2004). Older carers may be more vulnerable still, their double vulnerability posing a number of ethical challenges for researchers (Moore and Miller, 1999). The issue of how to involve vulnerable people in research without jeopardising their vulnerable status is a tricky one. One recommendation by Hanley *et al.* (2003) is to involve people as early in the research process as possible.

In this study I employed a range of measures to minimise the risk of older carers being exploited:

- Older carers were involved in each step of the research process, for example the diary/interview method was utilised to enable older carers identify the broad areas of interest that formed the basis of the focus group meetings;
- Older carers participated in the analysis of the data;
- Older carers were involved in validating the data;
- Older carers held the power of *veto* with regards to the data that was included in the final report;



- Monthly newsletters kept everyone in contact with each other and up to date with research activities;
- A focus group format was utilised to share information and collect the data (alongside the activities described earlier i.e. literature reviews, etc.);
- Information was provided to older carers on each aspect of the research process and to what extent it was possible to get involved;
- Older carers have been actively involved in discussing the findings with a wide range of audiences in seminars, national conferences and workshops (including contributing to modules on two different MA programmes).

To enhance the ethical stance of the study still further, a number of issues were kept under constant surveillance, i.e. the management of confidentiality was of paramount importance, especially in light of the fact that the focus group meetings took place over several months. Not only was there a large amount of information (interview transcripts and field notes) but the very nature of the reciprocal relationships between older carers and myself encouraged the sharing of personal information that, while adding depth and breadth to the study, was not included in the final report. For all of the older carers this was the first opportunity they had had to reflect upon a number of important issues, therefore it was necessary to set up access to an independent counselling service (before the study commenced) to ensure issues raised were worked through with a competent professional.

Although I was thrilled that older carers wanted to travel with me to present the findings of the study around the country, that in itself raised a number of ethical challenges. Because older carers choose to reveal their identity that meant that the stories they shared about the person they cared for suddenly came into sharp focus. While older carers freely gave their consent to participate in the study and to share their stories with a range of readers, the person they cared for was not in a position to do the same.

Was it wrong of me to encourage older carers to share in the final part of the research process when the research topic was their private lives? Did the older carers have the right to talk about their innermost fears and joys in such a public arena? Yet, was this not the very challenge that has kept the work of older carers all but invisible? All good questions with no easy answers.

### **Issues that older carers identified**

Older people want to be involved in research, but they are clear that they want to be involved in research that makes a difference (Reed, *et al.* 2006). This was a view shared by older carers taking part in this study who noted that the work they were undertaking was novel and could have far-reaching consequences in their small community.

*This is pioneering, isn't it?...hopefully a lot of good will come, more and more'.*

Although there was little doubt in my mind that older carers – because of their extensive life experience – had the knowledge, skills and expertise to act as co-researchers, I needed to convince them of that. Using naturally occurring activities, such as research diaries and focus group meetings to collect the data proved to be instrumental in enabling older carers to see how they could contribute towards achieving the aims of the study. During the study it came to light that this was the first time anyone had asked the carers to document their day-to-day life. The following quote illustrates how it was the 'everydayness' of the research tools that rendered them easy to use and how being involved in the research activities made carers feel valued.

*The atmosphere, the down-to-earthness of it, how we described our daily life, our daily working...I've never been asked to do that before...we weren't numbers any more, we have a rightful place in this life.*

Older carers also recognised the transformative effect that being involved in this research study had had on their lives saying,

*...you've given us a name, you've given us a place we never had before...*

### **Reflections on the research tools**

If older carers had been involved from the very beginning, it is likely that the focus of the study may have been very different. I write this because carers struggled with the idea that their everyday lives were interesting and it was not until the diaries were read aloud at the first focus group meeting that they began to see value in what they had written.

For me, hearing the diary entries read aloud was a very powerful and humbling experience. I was very aware of the privileged nature of the information I was hearing and of the effect that reading the diaries had on carers. While the diaries were being read, everything in the room seemed to recede into the background, except for the soft voice of the reader. It had the same impact on listeners as 'fly on the wall' documentaries do on television viewers, except more so. This was a real person (someone we knew), telling their real story, detaching from the experience was not an option. In a way, we became part of the re-telling of the story (Frank, 2000). It was without doubt an intensely emotional experience for both the reader and the listener. Would the same impact have been achieved if I had read the diaries as I had originally planned? I don't think so. Also, I think the study was immeasurably enriched by the inclusion of the anecdotal comments added in along the way as memories from earlier times rose to the surface, strengthening the weave of the story.

Asking carers to complete their research diaries at home had a number of benefits. For example, there was no pressure to complete the daily entries at a certain time of day, or even in a particular format. Carers wrote what they could, when they could. However, I presumed that if carers were uncertain of what they had written that they might ask for help from family

of friends, on this I was way off the mark. Without exception, carers had limited access to outside friendships and family members often lived some distance away. Also, I had not bargained on the fact that even though carers knew the diary entries would be shared with other carers, they wrote candidly on deeply personal issues. That the diaries were able to capture both the public and private lives of the carers was picked up by one older carer who revealed that she had never talked about her day-to-day life with her daughter who had learning disabilities – not even to her closest friends.

*And we can say to you [the researcher], and put it down, when you couldn't to your friends because they know you, and you wouldn't dream of talking that way really...*

### **Limitations of the study**

Every study is limited in scope due to time restrictions, funding or even just the experience of the researcher. This study is no different. When I first began to plan out the involvement of older carers in the study, I hoped to be able to facilitate at least five or six focus group meetings. However, due to the length of time it took to set up the first meeting with older carers (eight months after the study began), I had to drastically scale back the level and types of involvement that older carers could choose. This meant that the spectre of tokenistic involvement raised its head on a number of occasions. Due to time constraints, I was unable to facilitate the training sessions on research methods and approaches that older carers would have needed in order to take part a more active part in the study. Although I spent a part of each focus group meeting explaining the research process and what steps we needed to take to move on to the next stage in the study, it was by necessity only a brief introduction to what is a very complex process.

Also, because older carers could not be involved in the development of the research proposal (for this had to be agreed by the research ethics and governance committees before I could approach the older carers), I did not

always ask the right questions. For example, when they reviewed and edited the draft report, older carers felt it was somewhat lacking in demographical and biographical data. Older carers felt that the study would have been enhanced by the inclusion of a brief 'pen picture' of each older carer and their dependent, as this would have provided a richer context for their subsequent stories. Older carers also identified that the inclusion in the appendices of a complete list of all the issues raised by them, together with their suggestions for overcoming them, would have been very useful.

### **Concluding thoughts**

From my experience in working with older carers in this study, it has become clear that if they are to be more fully involved in research, service development or policy implementation and evaluation activities, then the responsibility for selecting the 'right tools for the job' lies first and foremost with funders and secondly with researchers. The tension however, between what funders want as an end product and the use of truly participatory methodologies is a precarious one (Reed, *et al.* 2006). I believe however, that using participatory research with vulnerable groups such as older carers has the power to be emancipatory. And, although not without its difficulties, emancipatory research is according to Lynch (1999, p.41) "...analytically, politically, and ethically essential if research with marginalised and socially excluded groups is to have a transformative impact". Older carers in this study experienced something of that transformative impact and were eager to be involved as much as their busy schedules allowed them to be.

It seems to me that if we are serious about involving our most vulnerable citizens in research, then we need to seek them out and meet with them in the streets where they live and in the ordinary spaces they share. If we do not, then the pattern of social exclusion will be inexorably repeated. I believe that an increase in the numbers of older carers in recruitment and sampling strategies would be an important step change in current research policy. It needs to be noted however, that involving older carers as co-

researchers requires time, patience, and skilful planning of almost epic proportions.

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